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資　料

How Parents and Children Build a Relationship in the NICU
From Narrative of Parents Who have Infants with Trisomy 18

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Issues of How Parents and Children Build Relationships in the NICU

In Japan, Perinatal Care Facilities with the NICU (Neonatal Intensive Care Units) have been established since the 1980s. Since then, patients in need of high-level care as a result of congenital disorders or problems occurring at the time of delivery have been taken to the NICU. Currently, there are approximately 360 NICU facilities in the country.

The NICU is a peculiar place. The NICU is lit by lights 24 hours a day on infant incubators neatly arranged. Inside the incubators are naked children, several and tubes are attached to their hands, their legs and their mouths. Electrocardiogram machines next to the incubators continually make an unnatural “beep, beep...” sound by the incubators. At the NICU where the author stayed for about two and a half months, everyone had to put on a white coat and a hat and then only after washing ones hands one can finally see one's child. The unit is a special place within a hospital. In fact some NICU facilities are blocked off by iron door.

To doctors and nurses who work in the NICU, it is a place where difficult treatments seem ordinary. To parents, however, it is surely a place of extraordinary scenes and times, a place where parents and their child experience life and death, sadness, joy, pain, warmth and confusion in this apparently inorganic place.

If a child is healthy, the relationship between parents and their child is

built continuously from birth through child-raising. However, if a child has a disability such as a congenital disease, the relationship is momentarily torn apart. The NICU is an environment in which raising of a child begins in the absence of the parents. Recently, parent-child contact has become possible in earlier stages, but parents have to accept the situation occurring without understanding what is happening to their child.

I would like to examine how situation children with trisomy 18 and their parents build a relationship in the peculiar space of NICU.

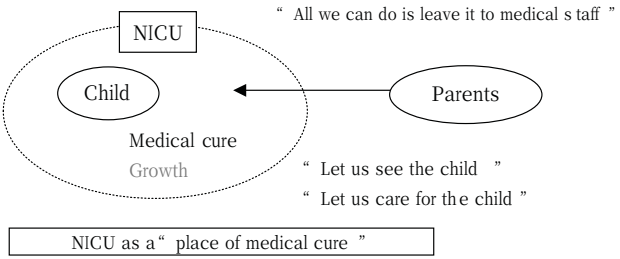

Figure: from Hashimoto, Yoko. NICU and Emotional Care, p. 117. Medica Publishing, 2000.

"What is Trisomy 18?"

Trisomy 18 is a chromosomal abnormality, characterized by delayed growth and development, as well as a host of complications. It occurs because there are three 18th chromosomes. In the 1960s, John R. Edwards and others reported the condition for the first time. It is said to occur in one out of 3000 to 8000 persons, and 94% with the condition children die before birth. In other words, 6% of these children are able to live in this world, and although they have trisomy 18, they can be said to have great survival power. According to textbooks of children born with trisomy 18, the rate of their survival to one year old is 10%; one out of ten of these children experiience their first birthday. However, in recent years, some persons can live until teens or twenties in the U.S. and Japan.

In Japan, reports have been made on the various complications and and the hardness of the vital prognosis of children with trisomy 18, but among the parents and at medical care sites, there has been a dearth of necessary information on how to perform medical care and manage health, and how the children and parents should actually share their lives.

Let me introduce a true story: When a genetic doctor went to an NICU at the request of a neonatal doctor, he saw a baby struggling to breathe. The neonatal doctor said "I want you to diagnose whether the child has trisomy 18 or not". If the child had trisomy 18, the doctor was not going to insert an artificial respirator into the child, yet if the child did not have trisomy 18, he was going to insert it into the child. Since the result of a chromosomatic test was not immediately available, he made the diagnosis on the spot by the child's facial expressions and other features, then decided whether or not to insert the respirator into the child based on the information.

While there are some hospitals where doctors try such proactive treatments such as tracheotomy or surgery for children with trisomy 18, there are other hospitals where doctors take such actions as considering limiting treatment after the diagnosis is made, and this has brought confusion to the medical staffs.

I gave birth to my oldest daughter in March 1997, but she passed away after 75 days because of trisomy 18. In 2001, I established a patient advocacy group called "The Trisomy 18 Support Group" (http://www.18trisomy.com/) in Japan, and now serve as its representative. Medical staffs tend to think that "life extention causes great pain to the child, and places a burden on parents". On the other hand, parents are confronted with a disease they have never heard of and to make matters worse, there is no treatment information. Moreover, doctors' explanations are full of jargon. Furthermore, parents are told that their child is going

to die soon. Parents naturally panic when they face a situation that relates to important moments in which their child's life. In such a harsh situation, the importance of child's existence to the parents and parent's feelings of love to children are beyond the harshness of the disability and prognosis. The Trisomy 18 Support Group has kept conveying the feeling of these parents to medical staffs.

"Studies Based on this Report"

This report is based on the results of a survey on actual conditions at NICU units an investigation that was conducted by the Trisomy 18 Support Group in Japan. This study was about children with trisomy 18 was the first to be conducted on a national scale in Japan. This study follows health studies of children with Trisomy 13 and 18 which were conducted by the American "Support Organization for trisomy 18, 13 and Related Disorders in U.S.A" (SOFT) (http://www.trisomy.org/index.php) and University of Utah Pediatricians. This study is the world's first comprehensive study that covers the medical care, lifestyle, welfare, and psychology of children trisomy 18.

The subjects of the study were Trisomy 18 Support Group members. The study was conducted from May to August in 2003. 125 surveys were sent to the members via postal mail and 88 surveys were returned; that is, I received a response rate of 70% . 81 responses came from parents whose child was born, and 7 came from parents who had had a stillborn baby.

The contents of questions concerning emotional care data were: 1. the existence or non-existence of emotional care at the time of explanation from the doctor and or the first meeting with the child; 2. the existence or non-existence of emotional care when the child was born and the parent's satisfaction the care; 3. The type of emotional care parents desire of medical staffs. The contents of questions concerning the medical data

were: 1. the history of pregnancy/delivery; 2. Post-natal management; 3. History of Rearing.

"The first Meeting with Our Child"

What feelings do parents have from the time they learn of the pregnancy until their child's delivery while they watch the mother's belly grow and look at ultrasound pictures of the fetus? Most parents pray for the birth of a normal, healthy child, purchase new baby products, and dream of their new family and life. However, what emotions do these parents have when they find out that their child has a disability?

Here is a summary of some impressions at the time of the first meeting with their child:

- They felt pity for the child because the child had various kinds of treatments such as the insertion of tubes.
- They didn't want to accept the child as their own because of the infant's external malformation.
- Until they saw the baby through the ultrasounds, they had thought the baby's face looked a little bit like a rabbit's. However, when they held the child in a towel, they were shocked to see that the baby's face was uglier than what they had thought.
- "Small! So very small! Why on earth is my child so small?!"
- They felt so sorry for giving birth to the child in this state. They thought the child was cute, and they loved the child. Yet all they could say was "I'm sorry".
- They felt so sorry for not being able to bear a healthy, normal baby.

They had various kinds of feelings, from confusion about the external deformity, differences between the image of the child they had imagined and the actual child, feelings of anxieties a for the burden for the child's treatments, and feelings of sorrow that the child might die.

On the other hand, there were also parents who felt their baby cute or the joy of finally meeting their child:

- The child was very cute and beautiful. “My child is the cutest baby I have ever seen.”
- The child still had pain due to the caesarian section, but parents were happy to hold the baby for the first time.
- “The child is really doing his/her best.”

When parents find out that their child has a disability, they used the internet to find information on the disease, or keep reading experience notes of other parents with disabled children. They want to find information about the prognosis and growth of children who have the same disability.

With the spread of the internet, increasing numbers of parents are creating home pages and sharing their experiences. Along with disease information, progress, and pictures of children, in many cases, they also refer to “Heaven's Very Special Child” by Edna Massimilla. “Heaven's Very Special Child” is included in the pamphlet “Stronger and Brighter - For Parents with Down Syndrome Children”, produced by the Japan Down Syndrome Society (formerly “Koyagi no Kai”). The original poem is said to have been entrusted as a message to Japanese parents who have children with disabilities to former Toyo Eiwa Women's College professor Toshiko Niwa by Sisters of the McGuire Memorial Home in Pennsylvania in the United States (Kida, Mitsushiro. “Deformity Medicine (Senten Ijo no Igaku)”, Chukoshinsho., 1982. pp. 49 - 52.).

When most parents read the poem, they are in the depths of despair, having received the news, and feel sympathy with words. The psychology of this may be that in the midst of the struggle to accept reality, they find acceptance by temporarily placing their child in another dimension as a “child

given from heaven". There is also an independent change from "parents who had a disabled child" to "parents chosen by their children". Put differently, it may be a departure from the social labeling of "parent of a disabled child" and feelings of personal responsibility. A. Solnit and M. Stark have said as follows: "Within 'the birth and mourning of a disabled child', a 'disabled child' s birth' is 'the death of the child [the parents] expected'. If that mourning process is not maintained and stabilized, the longing for the healthy child they hoped for will haunt them like a ghost, and continue to prevent the family from becoming close to their real children."

"The 'Routinization of Disaster' in the NICU"

Daniel F. Chambliss has said that even if certain things are thought as special, tragic, and grave in the outside world, they become ordinary in hospitals. He calls this the "routinization of disaster". The routinization of disaster consists of the routinization of emotion, routinization of death, routinization of the world, and routinization of outsiders. (Chambliss, Daniel F. Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics. London: University of Chicago Press, 1996. pp. 19, 24, 39, 51, 57).

The routines of medical staffs are extraordinally values to parents placed in non-daily spaces. And the routines of medical staffs deeply hurt parents and children unconsciously.

Parents desperately struggle to accept the complex feelings they have for their child as they meet for the first time. They defer to the values of the medical staffs, trying to act like "good parents", and try to deepen their bond with the child. Amidst this struggle, while they are trying to accept their actual child gradually, the routine words and actions of medical staffs are in fact setting back the parents' feelings.

1．Word of Birth

Medical staffs did not say “congratulations” to the parents who had children with disabilities. “Congratulations” are only given to the parents who delivered healthy children. Since they have created a new life, they should be told “congratulations”. Whether the child has disabilities or not is a totally different matter. Most members of the trisomy 18 Support Group said that the births of their children were not celebrated, and they wanted to be told “congratulations”. They were filled with a desire for their children's birth to be accepted as a valuable thing.

- They wanted some proof to feel that their children were vigorous enought that everyone respected them.
- It is necessary to have an attitude of saying “congratulations”, to all children no matter how sick some children might be.
- They wanted their children to feel that their life was blessed and they had the right to be loved by everyone.

2．Word of Death

Sometimes, in the presence of the parents' child who lives, it is emphasized that the child has no chance of survival, or that the child has little time to live. In hear the name of the disease for the first time parents panic.Some parents are deeply hurt by medical staff's heartless words, as the parents are normally in the pain and despair of losing their child.

In the case of trisomy 18, many parents receive explanations that limit theatments such as “we will not treat proactively”, or “we will not operate”. In some cases, the treatment policy is decided before their child's birth. It cannot be said that appropriate treatments based on children's condition are not chosen, but that doctors one-side deny possibilities of treatments so that they can live at ease. As a result, the parents feel that their child's life has been abandoned by the medical treatments. There

is some background for this. First, there is generally a lack of support to enable the child to live. Second, there is a lack of explanation and discussion between medical staffs and parents in the decision process of the treatments for the children.

- In the case of trisomy 18 , even if they are born, they don't survive so long. Therefore, it is not worth performing a caesarian section.
- When a tube was inserted into a child's mouth, or when a respirator was removed, etc., the parents were always told "the child might die" by the doctor.
- Parents were told "the doctor is busy with children who are living", even though their child was living, too".
- Parents were told "in the time left for the child" repeatedly.
- Right after birth, parents were asked by the doctor "Would you like to attend to your child at the infants deathbed at home?"

3. Child abuse

The more serious the disabilities are, the more medical care they require. Parents have seen medical staff members mishandle children's bodies. When parents feel children are not taken care it leads to mistrust toward medical staff. Sometimes parents have heard remarks from the medical staff that make the parents feel as though "the child is being used as a research subject". In other words, there is an issue of whether or not medical staffs respect or value children and their parents. The medical staffs involvement, who supports children and there parents if they respect the existence of children. Yet, if not, it hurts them deeply.

- Several medical staffs members held down a crying screaming child when it was being treated?
- A mother was asked "Why did you have a child like this? Did you do something bad?"

・“When I practiced breastfeeding, although my child did not have the jaw strength to feed, medical staff thrust the child's face into my breast. I still cannot forget the face of my suffering child at that time.”
・“When my child was gravely ill, the medical staff that made the treatment laughed, and I felt that “this is just a part of their job to them”.
・One parent was told “I have never seen a child live till one year old; I felt it was as if the child was a research subject.

4. Hiding of disabilities

Children with more serious levels of deformity tend to be hidden away. They are partitioned off in the narrow spaces the NICU, or their incubators are put in the back corners. They are “given consideration” and kept out of view. Medical staffs may be try to be kind to them. However, from the parent's perspective it seams that the staff feels the need to hide the child.

Many parents also have affection for the typical “overlapping finger” deformity found in trisomy 18 children. Some parents felt that the sixth finger which occurs in hyperdactylia was “cute like a cherry blossom” and felt that “my child was playing with the finger as it was their own toy.” The parent's viewpoint doesn't only focus on the deformity and disability, but on another dimension. They feel that the act of hiding shows the medical staff's valuation that having a disability is misery.

・The child's incubator was left in the very back of the NICU.

There were other cases in which, the child's symptoms were explained, no one listened to the parents feelings without interception, or no one has stayed with the parents during difficult times. These make the parents feels isolated due to the business of the medical staff's daily work.

These things influence not only the difficulty of communication

between parents and the medical staff in the NICU, but also the building of parent-child relationships.

Parents experience of care by medical staff (n = 76 %)	Yes (%)	No (%)	NA(%)
Got information of child's symptoms and condition.	81.6	15.8	2.6
Got information about support groups,etc.	38.2	59.2	2.6
Courteous physical care was provided our child.	92.1	6.6	1.3
Our child was treated as a responsive, cute baby.	90.8	6.6	2.6
We were able to personally bathe child or change child's deapers.	89.5	9.2	1.3
We were able to personally give milk to child or perform infusion or suction treatments.	67.1	31.6	1.3
Parent was given verbal comfort, encouragement, and advice.	90.8	6.6	2.6
Parent's feeling were listened to without interruption.	76.3	21.1	2.6
Workers chatted about things with parent.	81.6	15.8	2.6
Consideration was given so that parent could express desires and requests.	77.6	19.7	2.6
Medical staffs stayed with parents during difficult times..	52.6	44.7	2.6

Parents did not always necessarily have such experiences, “the staff allowed me to give care such as changing diapers and bathing”, or “They allowed me to give milk, or perform insertion, or suction treatment.” One problem is particular is that giving milk is usually done at intervals according to the medical care the hospitals' schedules and often dies not bit with the parent's system, and was not determined during parent's visiting hours.

“Building of Parent-Child Relationships Within the Medical Care System”

Inside the NICU, the parents' interaction with their child is monitored by the medical care system. The medical staffs think of interruption as a risk to

the establishment of the “parent-child relationship”. The standards for building parent-child relationships are made within the medical care system.

These include the number of visits, how many times breast milk is introduced, whether the parents speaks to the child, whether parents proactively asks about the child, and whether they gladly perform kangaroo care. Among these, bringing breast milk is a symbolic event that shows “parentness”. Parents who do not do these acts are judged to be “bad parents”.

Facilities with twenty-four hour of visiting at the NICUs are much more common than ten years ago, but there are still a lot of facilities that limit the visiting hours. The people who have interaction with the child most are the medical staff members. Parents feel that “even though I gave birth to the child, it's the nurse who's raising it. ”When the parent goes to visit the child with hopes of building a relationship with the infants, the nurses know their child better than they do. The parents then feel frustrated. Some even feel as if their child has been taken hostage. They can't say what they want to say. Sometimes they think “If I say that, maybe they won't change my child's diapers”, or “maybe the doctor won't check on my child”, or “maybe they'll be mean to my child when I'm not around”, and they become anxious. There are many cases where parents hold back from saying something, even if there's something they want to do for their child.

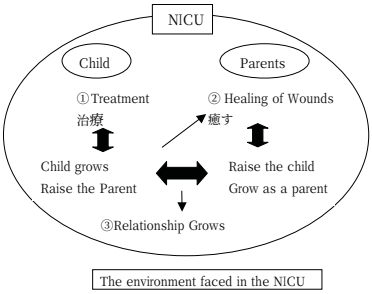

Figure: from Hashimoto, Yoko. NICU and Emotional Care, p. 117. Medica Publishing, 2000.

"Being As They Are"

Parents who have suddenly been told about their child's illness want someone to understand the situation they have been placed in. By feeling that their feelings are accepted and understood, parents minds are supported. Having someone stay there with them, and receiving gentle and kind words and encouragement from a fellow human heals parents.

Also, parents' feelings swing every day. They move between hope and fear about the condition of their child, and the way medical professionals care also affects them. Some parents also worry daily as they watch their child with tubes and respirators attached.

In the NICU, parents tend to act as strong parents. Sometimes they receive comments from the medical staff such as "you are parents, so you have to hang in there", or "You are the parents of the child?!", which can be painful for the parents. These comments can be construed to contain the medical staff's values of what a "good parent" is. Parents then put a lid on burdensome feelings such as pain, anger, and concern, in order to be a "good, hanging-in-there parent". It is important that parents have a person who listen to them, and also that they have a place to express their pain and anger. As the parents are often in shock and feel isolated, when there is someone to accept their feelings, the feel at ease that they are not alone.

Time to Be With the Child

Even parents who couldn't accept their child at first was gradually built a parent-child relationship as time goes by. On the other side of their feelings of "if only you hadn't been born", they remand his/her short-life as important. Many parents cannot accept their child 100% from the very start. Some parents gradually more parent-child interaction, and develop the relationship. Medical staffs tend to be more abrupt. Perhaps because time is short, they force parents to build a parent-child relationship with

the child. The speed of time passage might be different between parents and medical staffs.

- When a parent learned that their child has disabilities, they weren't able to accept it at all. They were filled with disgust. But after they heard the child had less than a year before they die, they felt a little better and tried to do their best to raise their child. Now, the child is over one year old, and having far exceeded all expectations, is growing stronger. The parent had at first thought that if the child had continued together with them several years with its high level of disabilities, they would come to hate the child, but now they don' t feel that way. They could, though, understand there such parents' feeling.
- When one parent was told their child was trisomy 18, they denied the child's existence for a while. They had thoughts such as "if only they hadn't been born", or "if only they had been lost", or "it would be better if they died before I get attached". The parent was confused about whether it was okay to accept the child in their heart, or if it was okay to deny their existence still they die. They wanted someone to say "This child has a precious life, and it is a valuable life that has been born, so let's do all we can do." Though they are confused now, they feel that they should embrace the child for its short life, and love it so there would be no regrets. Actually, the child is shining and flexible, and gives the parent a sense of peace.

Parents' Words

There are three word that are particular to the Trisomy 18 Support Groups.

One is "the rock hand ("gu no te" like the hand of a fighter)". From the

medical staff's point of view, the overlapping finger is one of the produced by trisomy 18 deformities. It is also one of the ways of confirming a trisomy 18 diagnosis A picture of. this locked first appears on the cover of the handbook of trisomy 18 Support Group handbook. By putting it on the cover, we show medical staffs that it is a “cute hand”, a “hand of affection”, and a “the source from which our child gives us happiness”.

The second is “acceptance of our child (“waga ko juyo”)”. The child medical staffs see and the child the parents see are different. Because medical staffs differentiate the children by disease name, they see by their disabilities. For example, there is a way of calling a child “____, a trisomy 18 baby”. However, parents do not call their child that way, and they want the medical staffs to compliment their child’s cuteness, and to show an attitude and parents the child. Parents don’t just want the medical staff to pay attention to the disabiled part of their child. Also, though they always disappointed by the the announcement of their child’s illness, they to gradually find some hope in their gradually growing child. This is not a future hope for their disabled parts, but a hope they have for their child’s growth.

The third word is “angel day (tenshibi)”. In cases of trisomy 18, parents are given a notice of their child's death alone with the doctor' s announcement of the birth. The short life means birth and death are always. While sharing and valuing the short limited time with the child, the word “death” adjoin, and carry fear. Looking at it differently, they distinctly feel "life” every day. Parents don’t call it the “death day”, but “angel day”. Parents who can't accept their child's death continue to keep their relationship with the child with although they have simply returned the angel to heaven. They continue child-rearing by participating in the patient group in substitution of their child who no longer has a body. The patient group is supported by this kind of feeling, even though after the

child passed away the parents related to medical care continue.

The words the patient group use with the medical staffs atend against the routinization of disaster and unconsciousness slips. Parent-child relationship building is not spoken of based on the term the medical care system. In medical care, specialization, parents have pain because they can't put into their own words. In the NICU is special space, “Parents are amateurs, and shouldn't talk about their child's care”, “Doctors have the initiative in the child's treatment. This is true within the medical treatment team and in the relationship between the doctor and parent.” The parents, who are usually listener to the medical staffs, uses jargon of the parent groups becomes the speaker. These distinctive words, from parents who have placed themselves in the medical care system, can be accepted, as they are fresh to the routinized medical staffs.

Summary

When a disabled child is born, building a parent-child relationship is no longer an individual affair but one which is placed under the monitoring of a NICU, it is a part of medical care. And there is no private space there, and the parents and child become part of the medical staffs' daily scene. There, in that unusual space, not only the children, but also the parents becomes subject to the monitoring of the medical staffs. On the other hand, from the parent's point of view, the NICU is the place where their child lives, and is an important place for building the parent-child relationship.

In the NICU, parents have no way to express opinions to the medical staffs. Though the parents might have different values than the medical staffs about the handling of their children or the words or acts of the professionals, it is difficult for them to say so. There is a holding back in the feeling that their child is being held was hostages, with medical staffs doing what they should be doing as a parent. Though a parent should go

through pregnancy, birth, and raising a child, the more serious the child's illness and handicap, the more the medical staffs, led by the doctors, have perform the rule in the NICU..

The values of the medical staffs, created within the medical care system, are a hindrance for building parent-child relationships, and are sometimes painful for parents. Often, when a parent fails to come to visit the child, or refuses to have the child move home, these sorts of actions are expressive of the parent's resistance to the medical staffs, and may be indicative of the pain of trying to act like a good parent.

The act of speaking in the distinctive words created by parents is designed to change the value of routinization of disaster by medical staffs. The habits and values professionals have inherited may be causing them to forget obvious to most people. Routinization in the NICU invites further disaster. Though the death of their child is one of the most important in the life of the parent, even the death of their child becomes a mere daily occurrence to the staff. Also, routinized events create the forcing of values and arrogant attitudes.

For parents to face their children's disability means carefully face own hearts. This may be only of painful, difficult feelings. However, as parents overcome them and place themselves in the medical system, they to weave together a story of parents and child in order to fill in the gap where their relationship has been interrupted.